

Summer
2023

Welcome to the Notts Branch Bulletin. We hope you enjoy reading about the latest fund raising efforts by branch members and supporters and don't forget if you are organising an event and would like to publicise it in the next Bulletin please contact the Branch Chairman or Secretary.

Race Night

After an enforced absence of four years (thank you, Covid!), we reinstated our biennial Race Night in March, at the Sir Julien Cahn Pavilion in West Bridgford. Around 100 enthusiastic punters were there and the atmosphere was electric, as people recklessly bet their 50p's, cheered on their horses, tucked into their baked potatoes or bid for great prizes in the auction.

We had great support from local businesses who sponsored every race and overall we raised £2,760. By any measure, a tremendous success, so a really big thank you to everyone who attended!



Treasurer's Report

The last three months have again seen some incredible fundraising and generous donations, resulting in total income for the branch of over **£9,000**. This included **£2,760** from our own Race Night (more elsewhere!), **£2,010** from the Radcliffe Male Voice Choir's Christmas concert, **£1,544** from Nottingham City Transport, **£800** from Rufford Park Golf Club, **£590** from Nottingham Masonic Lodge and **£250** from Viridian International. A big thank you to all our amazing fundraisers and donors!

In the same period we made 11 grants totalling over **£8,000**, including five riser/recliner chairs, a stairlift, wash/dry wc, washing machine, counselling and complementary therapy. In addition, five Cost of Living grants of **£350** each were made, funded by the national MNDA.

The 59 Club was won by Erica Littleworth in February, Gerry Thompson in March and June Ross in April. If you would like more information about the 59 Club, please contact me.

Roger Spells (Treasurer)

London Marathon – 21st April 2024

www.mndassociation.org/londonmarathon

Applications will close on 11 June, we'll let applicants know if they've been successful by 7 July 2024

Successful applicants will be asked to pay a £75 reg fee + minimum sponsorship of £2700

Second Thursday

At May's Second Thursday meeting we had the pleasure of a presentation from Sally Hughes, the MNDA's Assistant Director of Care. It was a really good, informative and interesting presentation covering a whole range of issues and aspects of the Association's work. After the presentation there were lots of questions and comments which lasted longer than her presentation and showed a lot of interest in what she had said. Finally what then made her attendance very welcome, and that little bit special, was Sally going round to everybody for a chat whilst they were doing the usual "mix and mingle". That allowed her to share more information but also give individual attendees the chance to ask more personal questions.

Charitique Charity Shop Cheque

Graham and Diane present a cheque for £3,500 to Carol Hughes, Secretary of the Nottinghamshire Branch

Graham and Diane have set up Charitique, a venture to support MND, a cause very close to their hearts, as sadly, they've lost two family members to MND in recent years. They've only just lost Angela, Diane's sister and in 2021 they lost their brother-in-law, Steve.

Charitique is a local support shop that opened in July 2022 and can be found at the Botany



Indoor Market, Mansfield, NG18 5NF on Tuesday nights from 5pm. Charitique aims to raise funds by selling new and pre-loved items – it relies on donations and offers a collection service in the Mansfield area. Graham and Diane also do a range of other fund raising activities including summer car boot sales. More information can be found on their website, www.charitique.co.uk or by telephone **07790819063/07595610817**.



On behalf of the Nottinghamshire Branch, a huge and heartfelt thank you to Graham and Diane for their hard work and wonderful donation and the best of luck for more successful fund raising activities.



How I got involved with MND - Theresa Angus

I first became aware of MND in 2003. I'd not long completed my post graduate studies in Birmingham and back home in Mansfield my Dad was having tests due to unexplained falls and speech difficulties. The Notts team diagnosed MND and at that point all Mum and Dad knew about the disease was what they'd seen on a documentary following Diane Pretty's story in 2002. Needless to say the news changed life for all of us.

Dad was 55 and told he had 18 months to 2 years. He of course stopped work, as did Mum as she became his full time carer, with myself and my brother there every weekend and school holidays to support. Mum and Dad attended the Second Thursday meetings back then and took myself and my brother along to one once, but we found it hard to see others with MND and face how things could progress for Dad. Mum and Dad benefitted from the support though and also benefited from the Notts branch Association Visitors, with one of their AVs being current and founder member, Jenny! They also had access to support through such things as house adaptations. We lost Dad in April 2005 and from that point became fundraisers for the MNDA, setting up a tribute page in Dad's name and climbing Ben Nevis on his birthday - as he had done on his 50th. Our learning journey through Dad's 2 years with MND meant that we realised things like the fasciculations, that we'd spotted months before anything else seemed off, were warning signs but because everything else was normal, we'd thought nothing of it at the time. Fast forward to 2017, it was the fasciculations that filled us with fear when my brother, aged 41, started experiencing them. We relived the heartbreak all over again when our worst fears were confirmed. Darren's MND journey was altogether different to Dad's. Dad had lost his speech first but Darren's mobility went first and declined rapidly, losing all movement from the neck down (Dad had still been able to signal to us with a thumbs up right to the end) He was however an absolute whizz with eye-gaze technology - a gadget Dad hadn't been able to benefit from - and amazed everyone with the speed with which he mastered it and communicated - and turned the TV on and off and switched channels etc - much to the amazement of his young children - he even documented his journey via eye gaze keeping a details diary hoping that one day his memoirs would be published.



Throughout Darren's 2 years with MND he continued to raise funds and awareness, taking part in the Sherwood Forest Walk to D'Feet, featuring on BBC radio Nottingham at the start of his diagnosis and again later on when he was communicating via eye gaze. As a family, myself, Darren and Mum, revisited the Second Thursday support group a couple of times - but it was an ordeal for Darren to be moved and dressed and transported and he also found it hard to see others with MND whose symptoms seemed to plateau whilst his symptoms advanced rapidly. He did benefit greatly from the Quality of Life grants though and we were able to make treasured memories thanks to those grants, including taking his children on a much needed break where we managed to get Darren hoisted into the hot tub with them on a Forest Holiday weekend at Sherwood Pines, just weeks before he died. We lost Darren in 2019 and added his name to Dad's tribute page, continuing the fight, raising awareness and funds. It was that year also that saw the loss of Fernando Ricksen to MND, also aged just 43 the same as Darren - and the diagnosis of Rob Burrow, at the same age Darren was and also with 3 young children similar ages to Darren's three children. The spotlight on MND has certainly been raised due to Rob Burrow and the sports community and as I'm writing this, a former friend and colleague of Darren's has completed the first ever Rob Burrow Marathon! And we can hopefully see a future that not only has the creation of the Rob Burrow Centre for MND, but also greater care and support for all and ultimately treatments and one day, a cure.

Theresa Angus (Social Media Lead)

Branch AGM

After the cancellation of the proposed March AGM due to the unexpected and only one day of snow, we finally managed to hold the 2023 AGM at our April 27 Meeting. The attendance for the meeting was good and after an informative Chairman's report, we were taken through a very positive Treasurer's report.

All of the current branch committee members (Simon Fotheringham, Roger Spells, Jim Ross, Jonathan Pykett, Erica Littleworth, Theresa Angus, Carol Hughes, Jenny Smith and Mike Cole) expressed an interest in remaining on the committee, with two new members (June Ross and Chris Bull) joining the committee. The only formal part of the AGM was when everybody present voted unanimously for all the committee to be re-elected.

Rob Burrow Leeds Marathon – 12th May 2024

fundraising.mndassociation.org/event/view/rob-burrow-leeds-marathon

Robin Hood Half Marathon – 24th September 2023

<https://www.robinhoodhalfmarathon.co.uk/pages/enter>

Dates for your diary		
7th Jun	North Notts Support Group	Bassetlaw Hospice, DN22 7XF 11am - 12:30pm
8th Jun	Second Thursday'	The Mapperley Plains Social Club 2:15pm
5th Jul	North Notts Support Group	Bassetlaw Hospice, DN22 7XF 11am - 12:30pm
13th Jul	Second Thursday'	The Mapperley Plains Social Club 2:15pm
2nd Aug	North Notts Support Group	Bassetlaw Hospice, DN22 7XF 11am - 12:30pm
10th Aug	Second Thursday'	The Mapperley Plains Social Club 2:15pm
6th Sept	North Notts Support Group	Bassetlaw Hospice, DN22 7XF 11am - 12:30pm

Branch Contacts

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